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Everyday functioning of people with Parkinson's disease and impairments in executive function: a qualitative investigation

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Abstract

Purpose: Executive function is the key area of cognitive impairment in Parkinson's disease.

This study investigated how cognitive difficulties impact on everyday life for people with Parkinson's disease and their carers, and whether they explicitly mention executive-type difficulties.

Methods: Semi-structured interviews with 11 people with Parkinson's disease and six carers were analysed thematically. People with Parkinson's disease performed within the normal range on cognitive screening tests, but all had abnormal scores on tests of executive function.

Results: Despite relatively mild executive deficits and no global cognitive impairment, participants described executive-type difficulties as well as a range of problems in other cognitive domains, such as memory, processing speed and apathy. Cognitive difficulties had a far-reaching impact on everyday life and their significance depended on personal circumstances, such as the level of responsibilities of the person with Parkinson's disease and the extent of available support.

Conclusions: By presenting subjective accounts of living with Parkinson's disease and cognitive difficulties this study improves our understanding of how the observed level of cognitive impairment translates into everyday functioning. The study results have implications for recognising cognitive difficulties and for planning support for people with Parkinson's disease and their families, and can help identify ways of promoting effective self-management.

Key words: neurodegenerative disorders, cognitive impairment, frontal-type deficits, dysexecutive syndrome, behavioural problems, neuropsychological assessment, interviews, psychosocial intervention

Word count: 8177 excluding references and tables

Implications for rehabilitation

- Treatment of Parkinson's disease tends to focus on the movement disorder, meaning that cognitive difficulties and their impact can be overlooked.
- Participants in this study had only relatively mild executive deficits, but described a range of cognitive problems, including executive-type difficulties.
- Cognitive difficulties have an emotional impact and can cause a range of challenges in everyday life, adding to the burden of physical symptoms of Parkinson's disease.
- Results of this study provide insights into how executive functions impairments translate into everyday difficulties in Parkinson's disease and have implications for planning support for people with Parkinson's disease and their families.

Parkinson's disease (PD) is generally thought of mainly as a physical condition, but a high proportion of people with PD experience some cognitive difficulties, particularly associated with executive function (EF) [1, 2]. For some people, these difficulties become severe enough to meet criteria for mild cognitive impairment or dementia [3-5]. People with PD are frequently reported to underperform in tests of EF, specifically in areas associated with attentional control such as in planning, reasoning, decision making, response monitoring, and managing goals [6-10]. Some studies highlight behavioural difficulties associated with executive function, such as apathy and perseveration [11, 12]. EF impairments are difficult to measure in isolation as performance in EF tests typically relies on some other cognitive functions [13], and EF impairments may impact on performance in non-EF measures. For example, difficulties in strategy generation or attention shifting may impair performance on memory tests, and memory difficulties may be easier to observe and report than deficits in strategy generation. Similarly, in everyday functioning, it may be rare to observe the effects of pure executive impairments. Despite numerous studies of EF in PD, there is still a lot that we do not know about executive impairment in PD [14-16]. There is much debate and research activity around selection and interpretation of neuropsychological tests [17-19], but there is little guidance on understanding and documenting the impact of cognitive difficulties on everyday functioning.

Questionnaire-based studies report that people with PD complain about forgetfulness, distractibility and slowness of thinking [20-22] and problems with self-regulation [23]. Over 30% of 1072 participants in the study by Barone et al. [24] reported difficulties in maintaining concentration, which made it one of the most commonly reported non-motor symptoms. Poor EF is associated with poorer everyday functioning and reduced QoL in people with PD [14, 24-29]. While studies of this kind document some of the difficulties people with PD experience, they elicit reports only in pre-defined categories and do not

capture the complexity of subjective experience or explain in what way the difficulties impact on everyday life.

Several qualitative studies have focused on the experience of living with PD [30-32], but none have focused specifically on cognitive decline or EF deficits. Interviewing people with PD who have some cognitive difficulties about their experience, and their families, may provide richer information about their experience.

As treatment and management of PD tends to focus primarily on the movement disorder, cognitive difficulties and their impact can be overlooked. Practitioners may lack the knowledge or skills to provide support with these difficulties. A better understanding of how the observed level of impairment translates into everyday functioning could lead to better support and treatment for people with PD and their families and help identify ways of promoting effective self-management.

This study aims to provide insight into the everyday functioning of people with PD who have mild EF impairments of the kind commonly reported for this clinical group, in order to assess whether and how the impairments of EF translate into everyday difficulties. We interviewed a group of people with PD who underperformed on a screening test for EF and at least one of the commonly used standard tests of EF, but performed within the normal range in general cognitive screening tests. As EF may impact on various cognitive domains and influence everyday life in a complex and indirect way, we analysed broad accounts of day-to-day life. We considered a spectrum of cognitive functions as referred to in a) explicit statements about cognitive abilities and b) descriptions of difficulties in managing everyday life attributable to underlying executive or cognitive impairments. To gain a fuller picture of the everyday functioning of the person with PD we asked a family member (here referred to as a 'carer') to contribute an informant perspective. Specifically, the following research questions were addressed:

1. How do cognitive difficulties impact on everyday life for people with PD and their families?
2. Do people with PD who have executive impairments and their families explicitly mention difficulties in executive domains, in line with the profile of cognitive impairments derived from neuropsychological assessment?
3. When people with PD describe cognition-related difficulties impacting on everyday activities, how do these descriptions relate to the cognitive categories typically identified in neuropsychological assessment?

Method

Design

The study employed a qualitative exploratory design. The study was a part of a larger research project considering executive functioning in PD; approval was granted by the relevant local research ethics committee and all participants provided written informed consent.

Participants

Participants in this study were a subgroup of the sample of people with PD described in Kudlicka et al. [33]. People with PD and no diagnosis of dementia were identified by the Consultant movement disorder specialist (JVH) from the Movement Disorders clinics in North-West Wales, United Kingdom, and informed about the study following their routine medical review in the clinic. People who expressed interest in contributing to a research project discussed the study with AK and were given written information. In addition, several participants were invited to take part in the study upon completion of their involvement in another research project. The interviews were conducted following a completion of the in-

depth assessment of EF, with additional written information provided and informed consent documented. Participants had mild to moderate PD (Hoehn and Yahr stages I - III) [34] and had no evidence of dementia and no significant depression. They were considered to have executive impairments, as indicated by a Frontal Assessment Battery score of 15 or below (2 SD below the mean reported for healthy controls [35]) and at least one abnormal score on the Delis-Kaplan Executive Function System (D-KEFS) battery of standard clinical measures of EF. The Delis-Kaplan Executive Function System scores were interpreted according to normative data published in the manual: as impaired for scaled score ≤ 5 (comparable to ≤ 1.5 SD below the mean), and as poor for scaled score 6 and 7 (comparable to 1.3-0.7 SD below the mean), traditionally interpreted as potentially indicative of clinically significant impairment or as borderline in the context of a comprehensive evaluation [36, 37]. Where possible a family member that knew the person with PD well was also interviewed.

In total 17 people were interviewed, 11 people with PD (seven men) and six carers. The majority of people with PD lived in the community with their spouses, two people with PD lived alone, and one couple lived in sheltered accommodation. All interviewed carers were spouses or partners of the people with PD. All the people with PD performed within the normal range on cognitive screening tests, but had abnormal scores on tests of EF. They had no clinically significant depression or anxiety as evaluated on Hospital Anxiety and Depression Scale [38]; HADS-depression score ≤ 9 , HADS-Anxiety ≤ 8 . Further details are presented in table 1.

((Table 1 near here))

Procedure

All interviews took place in participants' own homes and lasted approximately 40 minutes. The interviews were completed by AK following her several visits, during which other assessments were completed. Where the carer agreed to be interviewed, two interviewers (AK and LES) attended, and the person with PD and the carer were interviewed individually at the same time. Interviews were guided by an interview schedule. People with PD did not have a diagnosis of dementia and did not receive any specific feedback on their performance in neuropsychological testing; questions about cognitive abilities were asked sensitively in a neutral manner to avoid biasing the conversation. The interviewers probed for difficulties that could be attributed to executive impairments and cognitive difficulties more broadly, and aimed to elicit the impact of the impairments on everyday life, but without focusing exclusively on cognition. Typically they started with a broad question about PD symptoms, followed by more specific questions about daily routine and changes in everyday life since the diagnosis, including changes in remembering and thinking, focusing on tasks, planning activities and making decisions (e.g., Did you notice any changes in your routine since the diagnosis? Is there any particular reason why your wife took over paying bills/ keeping dates of appointments/why you do not enjoy reading anymore? Did you notice any changes in how well you can concentrate on other tasks?). The interviews were completed in a conversational manner, with paraphrasing and 'talking back' employed to verify the interviewer's understanding. All interviews were audio recorded with participants' consent and transcribed verbatim. To maintain confidentiality pseudonyms were assigned to participants. NVivo 10 computer-assisted qualitative data analysis software [39] was used to organize and manage the data.

Measures

Global cognitive abilities were screened with the Addenbrooke's Cognitive Examination - Revised [40] validated for use in PD [41], which also provides a Mini Mental State Examination score [42]. Mood was assessed with the Hospital Depression and Anxiety Scale [38]. In order to identify people with PD with frontal-type deficits participants were screened with the Frontal Assessment Battery [35]. Pre-morbid IQ was estimated with the National Adult Reading Test [43]. Executive functions were assessed with the Delis-Kaplan Executive Function System [37], which is a set of nine tests assessing key aspects of EF: Trail Making, Verbal Fluency, Design Fluency, Colour Word Interference, Sorting, 20 Questions, Word Context, Tower, and Proverb. See detailed description of the measures in Kudlicka et al. [33].

Data analysis

The semi-structured interviews were analysed by AK and LC in two ways. First, interpretative work was undertaken to identify difficulties relating to cognitive ability and to decide which cognitive impairments were reflected in the descriptions of everyday difficulties. This was necessary as neuropathological processes manifesting in cognitive decline are outwith normal experience and so could be difficult for people with PD and carers to describe explicitly. This part of the analysis incorporated a deductive approach due to the underlying hypothesis about the existence of certain categories of impairment and the relationship between these and everyday difficulties.

Secondly, an inductive analytic approach was used to explore the impact of cognitive difficulties on everyday life in PD. In line with a constructionist perspective data were subjected to thematic analysis to identify patterns in participants' description of cognitive difficulties. The analysis involved a recursive process of coding and analysing data in six stages, as described in Braun and Clarke [44]:

1. Getting familiar with the data
2. Generating initial codes – these were interesting features of the data relating to cognition and current level of activity, i.e. references to cognitive or intellectual abilities, contribution to daily chores, engagement in social and leisure activities, changes in the level of physical and mental activity since the diagnosis, reasons underlying the difficulties and any coping strategies.
3. Searching for semantic and latent themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

Initial coding was completed by AK to identify accounts of cognitive difficulties and the consequences of potential underlying cognitive impairment. The codes included explicit references to cognitive difficulties as well as descriptions of challenging situations or practical problems where performance relies on cognitive skills. There were also examples of difficulties with social interaction observed in the course of the interview. We did not treat these codes as conclusive evidence of cognitive impairments, but given abnormal scores in the standard assessment of EF the difficulties were treated as likely to reflect underlying executive impairment.

The initial codes were grouped into categories representing cognitive domains typically considered in current neuropsychological models [45]. This allowed us to establish whether participants explicitly mention difficulties relating to the executive domain, in line with the profile of cognitive impairments derived from the neuropsychological assessment. Thematic analysis was then conducted to explore the impact of cognition-related difficulties

on everyday life in PD. The codes and grouping categories were refined in an iterative process by AK and LC until consensus was reached.

Results

Cognitive difficulties in people with PD – ‘*I have to think twice these days*’

Codes relating to cognitive difficulties were grouped into six cognitive domains, as listed in table 2: global cognition and thinking, memory, attention, processing speed, apathy and other behavioural problems.

((Table 2 near here)))

All but two participants named a cognitive impairment or described a difficulty attributable to cognitive deficits in at least one cognitive category. The other two people with PD did not seem to engage fully in the discussion about coping with everyday activities, which may have been due to difficulties with social interaction, avoidance of a potentially-sensitive topic, or a personality trait. There were marked differences in the type, quantity and richness of evidence for cognitive difficulties between participants, but there were no distinct differences between the parallel person with PD and informant reports. The category most frequently described as problematic by people with PD was global cognition and thinking, followed by the memory and apathy categories. These were also the three types of difficulty most commonly described by carers.

With regard to global cognition/thinking people with PD commented on their intellectual ability and specific difficulty in tasks involving cognition, although the precise cognitive impairment underlying a difficulty was not always clear from the description.

Karen: *It's like being in a plastic ball and I feel I'm not there, I'm not with it.*

Dorothy: *I have to think twice these days. Make sure I've got everything right.*

There were also comments relating to planning and making decisions:

Barry: *I've found I can't make a decision. I dwell on it for two, three or four days for something trivial.*

Carers also often made general comments about cognitive abilities:

John's wife: *If I asked too many times to get what I want then it annoys him because I think he's not, he's feeling that he can't cope with it as well as he used to do.*

Karen's husband: *She becomes mentally confused.*

Gary's wife: *I think to go from being so intelligent to not being very intelligent in my opinion that must be the hardest thing for him and it's the hardest thing for me too.*

Memory was the second common category in people with PD, with general complaints about forgetting, prospective memory problems, and word-finding difficulties commented on and observed in the interview process:

Dorothy: *Can't always think of the word right off.*

Hugh: *I can remember all the birthdays but sometimes the birthday's gone if I don't think about it first.*

Karen: *I can be told something and then after a few minutes I've forgotten it.*

Memory was the most frequent category in the carer interviews:

Karen's husband: *So the fact she's been told verbally, and she had read it had not sunk in.*

Collin's wife: *I've caught him with a couple of times, he doesn't turn off the grill.*

People with PD mentioned difficulties with attention and the impact of these on the ability to remember:

Eileen: *I can start a conversation, start saying something and then I can't finish it because I can't remember what I was going to say.*

Gary: *I just don't concentrate. I feel I'm not concentrating enough to remember what she's said.*

Hugh: *You can't absorb it like I used to absorb it erm your just sort of reading words.*

Carers commented on attention less often, possibly as it is less accessible to an observer in the relatively mild stages of cognitive impairment:

Karen's husband: *She has difficulty in holding on to a concept.*

Gary's wife: (...) *he's probably in a couple of hours only read six pages.*

Similarly, processing speed was mentioned more often by people with PD than carers. Carers commented on the speed of carrying out activities, rather than cognitive processing speed only:

Eileen: *By the time I'd thought of what I wanted to say, the conversation would have gone on tenfold.*

Florence: *It's just automatic for me to do these things slowly.*

Florence's husband: *You've just have to, gotta have a bit of patience 'cause she does things slow.*

Examples of behavioural problems were described by people with PD as well as by carers.

Apathy was one of the most frequently acknowledged difficulties by both people with PD and by carers:

Eileen: *I think a lack of energy but a lack of interest as well [is a problem].*

Gary: *Some days I really don't wanna go out the house really.*

Participants described some rigidity in thinking and behaviour:

Dorothy: *It doesn't matter what I do in that last hour but I must be ready to go. Just in case.*

Ian: *[Consultant] is of the opinion that it might be impulsive behaviour, compulsive behaviour [buying another car]. He was sure the model aircraft was and he thinks this is part of it.*

Karen's husband: *She will stop what she's doing to scrape it off because she's seen it she's got to do it then.*

Finally, examples of difficulties with social interaction were noted for John who offered a monologue about his and his wife's physical health and did not invite any questions, and for Alan who frequently went off topic and talked at length about unrelated matters. Dorothy made several comments that were seen by the interviewer as rather intrusive, for example:

When are you planning on marriage? (...) What happens if you have a baby?

Oh I've got indigestion again. Oh dear me. Feels like a lump of lead in the bottom.

Collin's wife commented on angry outbursts:

(...) but lately he's worse at it. I don't know whether that is with the Parkinson's or just cos he's a grumpy old man or his age or what you know but there's a lot of that in it now and words he'll say that I can't repeat on a tape or even to you, you know, about the driver in front.

Impact of cognitive difficulties on everyday life

This part of the analysis focuses on the impact of cognitive difficulties for managing everyday life in PD. Overall functioning is influenced by numerous factors and comments on cognitive difficulties need to be considered within that broader context. People with PD were often affected by physical symptoms of PD and other health problems, and there were also differences in personality, family context, responsibilities, and resources, all potentially impacting on how executive deficits are experienced. Below we discuss areas of life affected by cognitive difficulties, and we outline two prominent themes relating to withdrawal from activities by people with PD and the carers' needs for support.

People with PD commented on cognitive difficulties affecting several aspects of their lives: 1) daily routine, 2) social life and relationships, and 3) emotional experience. Their carers appeared to have similar views and often gave similar examples of cognitive difficulties in everyday life.

Karen: I can be told something and then after a few minutes I've forgotten it.

Karen's husband: The fact she's been told verbally, and she had read it had not sunk in.

Daily routine – "I just do the rubber stamping now"

Cognitive difficulties impacted on household management and various activities of daily living, as described by people with PD:

Ian: Yes, it does give problems, it does give problems because eventually a lot of those jobs I still have to go back and do them the right way (...) I'll start using nails for a given job and I'll think 'I shouldn't be using nails I should be using screws because the nails aren't going to hold the job as well as screws are' but I don't change, I carry on hitting the nails in. It sounds ridiculous, but it's the way it works for me anyway.

Gary: For some reason I can't work the petrol pumps correctly so I end up going to the kiosk anyway.

Their spouses gave similar descriptions:

Collin's wife: Yes, yes, he doesn't concentrate, he doesn't finish anything, he'll start something and then he'll say 'I've had enough of that', and leaves it you know.

Karen's husband: [She] will say to me, 'please will you telephone so-and-so, I want to order a dress' or whatever it might be and I say 'well why don't you do it, you know what you want to do' and she doesn't want to because she's

uncertain of herself because she's no longer fully in control of the pattern of her thoughts or fully in control of the words coming out of her mouth and that's all Parkinson.

Difficulties arose particularly for the more cognitively demanding tasks, such as managing finances, planning, making decisions and using technology.

Gary: *I just do the rubber stamping now [about making decisions].*

Ian: *I get into a programme that I've used for years, get part way through it and I suddenly don't know what to do next. (...) I don't know, technology, I'm having more difficulties with it than I ever had.*

Hugh: *I want to get on e-mailing and I'm gradually developing it myself. I did go to, I went to erm college before I got my computer (...) I didn't retain enough of what he taught me to make it useful to me.*

Comments on such difficulties were also offered by carers.

Gary's wife: *He won't use the web you see, he won't use a computer, he won't use a mobile phone, technology is like going over his head.*

Gary's wife: *Perhaps I'll say 'oh will you pop down to Aldi and will you get one or two things'. I think if I sent him to Tesco with a list it would faze him out.*

In relation to PD specifically, participants commented on difficulties in managing medication and appointments:

Karen: *I wouldn't say I never forget, I have occasionally or taken them later.*

Collin: *She remembers, reminds me to take me Warfarin.*

Collin's wife: *Oh no I do [remind Collin about tablets], he wouldn't take it, he would forget to take his medication. I've got it all in, you know the pill boxes, each day.*

Karen's husband: *She will get confused as to the day and so we have turned up somewhere and been there usually the day before rather than the day after thank goodness.*

Engagement in leisure activities could also suffer because of cognitive difficulties:

Hugh: *That's right yeah you can't absorb it like I used to absorb it erm your just sort of reading words. I do sort of, used to enjoy reading, but it's got to be something that really sort of grips me, really gets hold of me erm and it's got to be on my favourite subject of military.*

Florence: *I find it difficult to concentrate on reading if there's somebody in the room asking questions or interrupting, you know, the flow.*

Gary's wife: *I can see Gary will read but when I look, I perhaps occasionally see what page he's on before he starts and what page he's on when he finishes and he's probably in a couple of hours only read six pages.*

Florence's husband: *I think she's lost a bit of interest to tell you the truth.*

Mobility could be affected by cognition, for example where a person was not able to drive or otherwise lacked motivation and confidence, contributing to withdrawal from daily activities:

Karen: *I'm not driving because I don't feel I'm safe on the roads.*

Eileen: *Yes, I think I'd find reversing a little difficult, and yet I used to be so good at it I could reverse into very small spaces.*

Karen's husband: *If I'm not available, she will walk down to the hairdressers by herself or walk back from the hairdressers by herself but she feels very much more comfortable if I walk down with her.*

Emotional impact – “I don’t know why I’m like this”

People with PD frequently commented on low confidence and anxiety in relation to underlying cognitive difficulties:

Hugh: *I used to be extremely confident. I used to like stress, stress, I love stress. Bring it on you know. (...) It was good, stress was good, so it used to stimulate me. (...) I hate it now.*

Karen: *Sometimes I get fussed.. er... I’m on the phone. If I’m ordering something, I think ‘have I done that right’, which is not a thing that would happen before.*

Carers only rarely commented on cognitive difficulties having an emotional impact on people with PD, but a few noticed lower confidence and increased worry:

Barry’s partner: *I’m sure he could manage (...) but he is scared of trying to go away [on holiday].*

Karen’s husband: *It has immensely lowered her self-confidence she will say to be ‘I want to go to Marks and Spencer’s in L...’ and I’ll say ‘well let’s go now’, ‘oh no, let’s put it off’ and she very much wants to put things off.*

While some people with PD mentioned cognitive difficulties explicitly, others did not seem to recognise their significance or impact; even those who did notice changes might nevertheless be confused or frustrated by the change, with a feeling of loss and self-blame:

Hugh: *I don’t know why I’m like this, I don’t know and I may not be able to fully explain the reasons why and that annoys me because I was... I was fairly clever when I was younger.*

Gary: *If the credit card statements come or the bank statements, she’ll deal with all of that now. (...) I don’t know why it’s that way. Maybe I’m lazy.*

They might attempt to minimise the evidence of a change by trivialising it or with humour:

Karen: *I've never liked accounting anyway, or anything to do with money, unless it's spending it.*

Carers similarly struggled to understand how cognitive difficulties impact on the functioning of people with PD or to appreciate their significance. Karen's husband offered many eloquent and insightful comments about Karen's cognitive difficulties, her physical problems, and changes in confidence, but perhaps struggled to appreciate her cognitive difficulties:

Karen's husband: *On Sunday night we had guests here and she prepared a meal, so it's not impossible. It's that she sees the problems as being large. (...)*

No reason she shouldn't go, she is perfectly capable of going but it's outside the comfort zone and she doesn't want to make the effort.

Signs of apathy may be puzzling and frustrating. As in the examples above, the person with PD may appear to be not trying hard enough rather than potentially struggling with a PD symptom.

Anxiety was described by several people with PD in various contexts. In some cases it appeared to be a response to the challenges of living with PD, and difficulties caused by cognitive impairment might potentially exacerbate the worries. Other accounts of anxiety seemed to illustrate a manifestation of an underlying generalised anxiety. For example, Gary experienced on a few occasions a difficulty operating a cash machine and using self-service petrol station pump machines, which made him wary of using them:

Gary: *I shy away from going to a cash point, that's simple enough isn't it but that's one of the stupid anxiety things.*

However, he recognised that he was worrying in various situations and saw his anxiety as inappropriate:

Gary: *I suffer from anxieties. I worry about simple everyday things like I know you, I've met you several times but it still crossed my mind more than once that something different was happening today. (...) We like to go on holiday and just simple things like checking in at the airport, all those things when you go abroad erm you start worrying about that weeks before*

He underplayed his anxieties by indicating they were the result of having 'too much time to think'.

Social life – "He's not what he used to be"

People with PD commented on withdrawing from social activities due to the effort involved in reaching out to friends or simply in being part of a conversation:

Eileen: *I think I'd come to just be a hanger-on, just sit there and let everyone chatter around me. I'd end up going to sleep sometimes because I wasn't really concentrating because I felt it was such an effort to give, to be part of the conversation.*

Gary: *They call me more to be honest. It's no wonder I haven't got any close friends, I don't make the effort to get in touch with them.*

Gary's wife: *Sometimes usually because of the head [headache] we've had to cancel things because he didn't feel like going and going to things where you know he was with familiar people.*

Withdrawal from social activities impacted on carers, who might struggle to find a way of supporting their spouses while maintaining their own lifestyle:

Barry's partner: *He won't really push himself to try either because I'm sure he could manage [a holiday break in a hotel].*

Gary's wife: *I can't, I don't want to be chained to the house cos I think that would be bad for him, it would be terrible for me but it would be bad for him as well, you know,*

you've got to jolly him along and you know but it does affect your life no doubt about it.

They also noticed that the changing ability of their partner influenced the dynamic of the social group, and experienced feelings of loss:

Gary's wife: *Everybody is very supportive really erm but it's hard you know to go out with your friends because he's not what he used to be.*

Relationship with carer – “You've got to jolly him along”. The relationship between the carer and person with PD gradually became less of an equal partnership. Carers became more involved in carrying out chores alongside people with PD, and then as people with PD became gradually more reliant on them, they might take over these responsibilities altogether. This increasing dependency was not only due to physical limitations, but also to changes in cognition, even though cognitive impairment in the sample was relatively mild:

Florence: *Combined effort, you see, we do things together.*

Eileen: *When you're married to someone who's got so much personality, I tend to let [my husband] get on with it. I rely on him to do the talking for me. It's not right on me really but he doesn't mind.*

Karen: *I'd need my husband here to tell you because he... I don't get my words out, I don't think of the words. I fuddle around if you know what I mean by that (...) I rely on my husband more, and I think in a way that's a pity for him.*

Differences in understanding of the situation and in expectations added to the burden of living with PD, as people with PD and carers struggled to understand and communicate about cognitive difficulties:

Gary: *Well, I've got a feeling she doesn't involve me as much as she used to (...) Well, like if the credit card statements come or the bank statements, she'll deal with all of that now.*

Karen: *I let him get on with it because he's there before me.*

Karen's husband: *She gets very very frustrated with herself at not doing these things and then gets angry at me because I'm doing them because somebody's got to.*

Differences in how people with PD and their carers perceived person's ability and their changing roles could lead to frustration and bitterness:

Karen's husband: *In fact, if I was suddenly to die she could overcome quite reasonably. It would take her sometime but it's a perception that she can't do it rather than an inability.*

Hugh: *My daughter is the one who says 'I want you to get checked for your driving dad'. Children are terrible when they get in charge of the, she's in charge of me so she says.*

The relationship with the carer is linked to a broader theme of carer's support and expectations that is discussed below.

Carer's expectations and the support they provide

The extent of difficulties encountered by people with PD in daily life depends on several factors, not only the actual physical or cognitive impairment. One element is the person's prior level of involvement in daily activities and personal expectations regarding level of independence. For example, a person with PD who is not responsible for managing finances is unlikely to face a problem relating to paying bills or writing cheques:

Collin's wife: *He doesn't know how to do anything, he doesn't know how to turn a washing machine on but he never did, you know, that's nothing new, you know.*

People with PD who have others willing to take care of daily chores will have a different experience of physical or cognitive symptoms than those who can only rely on themselves:

Barry: *As I say, I'd be lost without my partner. Yeah, I really would be lost;*

Gary's wife: *I find if it's anything quite complicated he gets, he gets quite stressed about it so you try not to, you try to sort of avoid, I just take it as that's just something I do.*

As discussed earlier, the relationship between a person with PD and carer, and the nature of the support given, changed over time. Carers supported people with PD by encouraging independence and by gradually relieving them of the difficult chores, balancing between the two to match the abilities of a person with PD:

Gary's wife: *You know you've got to sort of try and praise him for what he can do erm not always be at him for what he can't do.*

However, adjusting the level of support to the person's changing abilities could be a difficult task, as discussed below.

Empowering vs. expecting too much

Carers supported people with PD by encouraging their independence through prompting and encouragement to maintain involvement in everyday activities:

Florence's husband: *When she says 'I'm slow', I say 'ell you're still doing it.'*

The person with PD could indeed see the carer as a source of support and motivation in the struggle with PD:

Eileen: *It's a battle against life, and it's up to me to get the best and most out of it I can for [husband's] sake more than my own.*

However, where there was a discrepancy between people with PD and carers in perceptions of the person's ability or in what they both considered appropriate support, the carer's encouragement could come at a price, with increased frustration and anxiety:

Eileen: *Well I rely on my husband for transport. He's trying to persuade me to use the bus, but when you're used to a car... I'm not so keen on buses.*

Gary: *I don't know why it's that way. Maybe I'm lazy (...) Oh she [wife] definitely thinks I am. (...) Not intentionally I'm not. I don't intend to be.*

Hugh: *[I'm organised] to my standards but not to my daughter's standards.*

Ian: *Incidentally that's another thing my wife gets annoyed about, I can't keep still.*

The carer's support might be seen as threatening the independence of the person with PD:

Dorothy: *He [son] bosses me around (...) he didn't have much to do with my finances until quite recently actually.*

Hugh: *I've tended to, not exactly push her back, but hold my ground a little bit erm I think that she could, my daughter could take over very quickly.*

Florence: *[Husband] will say, well, don't struggle with it, I'll do it for you; but I don't want to always want him to do it, I want to do it myself.*

Relieving from chores vs. deskilling

Some carers tried to avoid the person with PD having to confront difficulties, in order to protect them from anxiety and frustration or ensure safety:

Gary's wife: *You don't always want to be bringing it to his attention that he can't do, he used to be able to, but he can't do it because that's the last thing you should do in my opinion.*

Colin: *We're going on the train cos [wife] said 'you're not driving all that way' cos it is a long way.*

Adjusting expectations of the ability of the person with PD ability could make it necessary to take over responsibilities:

Collin's wife: *Oh he was forgetting to take it, terrible, yeah, so now we know you know he takes it, well I remind him.*

It could also reflect carers' preferences or a long-standing division of responsibilities:

Barry's partner: (...) *he's happy to drive but I'm not a good passenger so I'll drive.*

Collin's wife: *He doesn't know how to do anything, he doesn't know how to turn a washing machine on but he never did, you know, that's nothing new, you know.*

However, it could also bring a risk of deskilling the person with PD and of frustration for the carer:

Karen: *I've got little containers so I can see Monday, Tuesday, Wednesday, and so on, and he does those because apart from being very helpful, he's a bit of a control freak so it suits him to do those (laughs).*

Adjusting to cognitive decline in people with PD required empathy and insight, and was no doubt a painful journey:

Gary's wife: *[Gary's granddaughter] is how old now erm nearly eight months and I think she'll be brilliant for Gary you see because he'll be able to do, you know read little stories I mean he finds concentration and reading a book quite hard but little stories for children and little jigsaws, that'll be good for him [gets emotional].*

Withdrawal from activities – 'She doesn't want to make the effort'

Reduced involvement in everyday activities was a prevailing theme in the interviews and a complex phenomenon that requires separate consideration. Low motivation and lack of energy were frequently described by people with PD and carers and appeared to influence all aspects of everyday life:

Florence: *I feel sluggish (...) I find it a big effort to do things*

Karen: *I'm not going out so much and doing things, I try to because I think it's a good thing to do. (...) It's like being in a plastic ball and I feel I'm not there, I'm not with it.*

However, the motor symptoms of PD could make an activity genuinely more demanding and so less enjoyable:

Florence: When I'm not having a particularly good day, I feel very lethargic. (...) I don't want to get up and I have to push myself and make myself do things and get up and get on with it; [Husband] thinks I've not got as much interest in the garden now as I used to have, and I...I can't say that that's strictly true. I do still enjoy my gardening but it's...it's more of a hassle to me now than it used to be so I find it more difficult, I suppose.

Withdrawing from activities might therefore be a reaction to increased physical or indeed cognitive difficulties rather than a symptom of apathy:

Eileen: I wasn't really concentrating because I felt it was such an effort to give, to be part of the conversation.

It might also act as a coping strategy to avoid confrontation with a difficulty. For example, Karen and Gary were both aware that they are no longer involved in managing finances, but neither indicated that this was because they found it difficult:

Karen: Whereas before I would deal with financial matters, I tend to leave them now. Erm... I've never liked accounting anyway, or anything to do with money, unless it's spending it.

Gary: Well I was, before I retired, I did all of that, she didn't do anything in the bills or, but that's flipped right round now. (...) It just came to be the way it is now, it wasn't planned.

Discussion

To our knowledge this is the first qualitative study focusing specifically on cognitive functioning in people with PD with executive impairments [14, 15]. We aimed to examine

how cognitive difficulties impact on everyday life for people with PD and their carers, whether executive-type difficulties are explicitly mentioned by people with PD and their carers in line with their neuropsychological assessment results, and which other cognition-related difficulties affecting everyday activities are described. Although there were relatively mild executive deficits and no global cognitive impairment in the study group, participants described executive-type difficulties as well as many problems across a number of other cognitive domains, and these had a far-reaching impact on everyday life. The study extends our understanding of executive deficits in PD by presenting subjective accounts of living with PD and cognitive difficulties.

Recognising EF-type difficulties

There is limited research on self-reported cognitive difficulties specifically in people with PD with EF deficits. Koerts et al. [23] focused on executive difficulties, but in a general sample of people with PD without dementia, and the report did not include any details of which particular difficulties were reported. In our study explicit descriptions of specific executive-type impairments were rare, but participants gave some descriptions of difficulties in thinking processes, attention and behavioural disturbances, and some of the memory difficulties seem to reflect frontal-type problems, for example prospective memory difficulties or not registering information due to poor concentration. This links to the study of Copeland et al. [22], which found that executive impairment was the second most common deficit according to standard tests (67% of people with PD), but only 14% of people with PD and 12% of carers acknowledged it in the interview. In this study people with PD and with PD-Mild Cognitive Impairment and their carers indicated the absence or presence of cognitive deficits in five cognitive domains and the responses were compared with their performance on neuropsychological assessments. The reason why people with PD and carers rarely name a specific executive deficit may be the fact that elaborate theoretical concepts of EF do not

translate into everyday language as easily as memory problems or word-finding difficulties. In Copeland et al. [22] EF were explained to people with PD as “difficulty finding solutions to unexpected or previously encountered problems, organisation, planning, sequencing tasks in everyday life, judgment and decision-making, problems completing tasks” (p. 696); although it is a relatively detailed description it does not include behavioural-type difficulties, such as apathy or difficulties with social interaction, and it could be too abstract for a lay person to relate to. People with PD in our study did not use terms like sequencing or judgment, but the difficulties in carrying out daily activities that they described do suggest some underlying executive-type impairments.

Non-EF cognitive difficulties described by people with PD and their carers

Cognitive difficulties described in the interviews were categorised into six cognitive domains: global cognition and thinking, memory, attention, processing speed, apathy, and other behavioural problems. Account of non-EF cognitive difficulties may be a sign of a decline in other cognitive domains not picked up in cognitive screening, but could also reflect the fact that EF impairment may indirectly influence other cognitive domains [13]. As discussed above, it may also relate to issues around recognising and naming specific executive abilities.

Our study appears to be in line with several questionnaire-based studies indicating that people with PD without dementia self-report forgetfulness, distractibility and slowness of thinking [20, 21, 24]. Memory was the most commonly-reported impairment in Copeland et al. [22] and it was also well-represented in our study, while our most frequently endorsed category of global cognition and thinking did not have an equivalent in that study. Low accuracy in reporting the absence or presence of cognitive impairments highlighted by standard tests could be interpreted in terms of low insight [22]. However, in our study there were no obvious difficulties with estimation or self-rating of cognitive abilities among people with

PD. Some carers were more explicit than people with PD when describing difficulties, but generally similar observations were offered, in line with a previous study [46]. Generally low ecological validity of neuropsychological tests may mean that poor performance in one test does not imply a significant functional impairment, particularly if the test measures an ability can be easily compensated for. Self-reports could be influenced by low mood although in our group participants reported no clinically significant depression or anxiety. Finally, self-reports of cognitive difficulties may be influenced by the ability to recognise, name and remember a difficulty, and readiness to discuss it with the interviewer. In our study the most commonly named impairments were also those that are relatively accessible in common language, although the analysis suggested that the impairments underlying reported difficulties may be more intricate.

Studies investigating frontal-type behavioural disturbances in PD tend to focus mostly on apathy and more cognition-related problems, such as distractibility [47, 48]. There are well-described impulsive behaviours and abnormalities in novelty-seeking linked to PD and antiparkinsonian medication [49], but there is less established evidence of difficulties with social interaction. In our study there were a few examples of behavioural problems. Some accounts of rigidity in thinking seem to reflect punding - stereotyped, unproductive, complex behaviours observed in some people with PD on high doses of dopaminergic drugs [50]. We noted many examples of withdrawal from activities, which can be taken as signs of apathy, a clinical symptom potentially caused by changes in neuronal circuits connecting the prefrontal cortex and basal ganglia [51]. Apathy is frequently reported in PD literature and there is evidence for a relationship between apathy and impaired executive function in early PD [52, 53].

Impact of cognitive difficulties on everyday life

Our study shows that while many of the challenges of living with PD relate to physical symptoms, even selective and mild impairments can add to the burden. They have an emotional impact and can cause a range of difficulties in everyday life. For example, technology and finances can get increasingly complicated, concentrating on reading or a conversation becomes more an effort than a pleasure, there might be missed appointments, missed doses of medication, and gradually the spouse may have to take over planning and decision making. As a recent qualitative study showed, apathy may have a profound impact on everyday life of people with PD [52] and can be particularly frustrating for carers of people with PD [54]. Our analysis suggested that withdrawal may be caused by multiple factors; it may be how the overall burden of the disease manifests itself rather than a result of frontal-type neuropathology, in line with the results of an interpretative phenomenological analysis of the experience of apathy in PD [55]. It is advisable not to assume apathy is an endogenous difficulty and instead to address it within a broader psychosocial context [56]. The analysis showed how different personal circumstances and level of responsibilities among people with PD may impact on how they experience cognitive difficulties. Those with more support from family and friends who have an option to avoid certain tasks might be protected from confronting their difficulties. However, carers may struggle to understand and adjust to changes in their partner's cognitive abilities, which leads to tension and misunderstanding.

Implications for clinical practice

Results of this study have implications for recognising cognitive difficulties in PD and for developing support programmes. Executive impairments are frequent in people with PD and may have a noticeable impact on everyday functioning, but are notoriously difficult to discuss in lay terms. They are likely to be entwined with the impact of motor impairment and masked

by withdrawal and the carer taking over responsibilities, making it even more difficult for people with PD to recognise as specific impairment and to report it in a clinical interview. It is crucial that clinicians have good understanding of the potential impact of EF deficits on everyday life in order to ask the right questions, educate and support people with PD, and ultimately improve the accuracy of diagnosing cognitive difficulties in PD. When enquiring about potential executive impairment during a clinical assessment it is important to probe with plenty of examples and include questions about more general cognitive abilities, such as those relating to EF. It may be more appropriate to assess changes in participation in everyday activities in the context of earlier involvement, significance of physical impairment and available support, rather than asking about specific executive impairments. Recognition of cognitive difficulties will open opportunities for developing support programs that account for executive impairment in the context of other difficulties impacting on life in Parkinson's disease.

Psychological therapies and functional interventions can potentially help in compensating for cognitive decline and reduce withdrawal from activities, but in order to be successful they need to account for complex interactions between physical impairment, cognitive decline, apathy, anxiety and social context [57, 58]. In particular a focus on physical impairment or a premature assumption that problems are due to apathy can reduce the chance of understanding and addressing the effects of cognitive decline with appropriate support.

Limitations of the study

It is important to acknowledge some limitations of the study. As our sample consisted of people with PD with selective EF impairments and with above average estimated intelligence level, the results might not be representative of all people with PD. Cognitive assessment was undertaken as part of a research project rather than as a clinical evaluation, and so participants were not given feedback about their abnormal scores and there were no questions

implying cognitive impairment during the interview. This reduced the risk of people with PD exaggerating or over reporting their cognitive difficulties, but also meant they could not be asked directly about executive impairment or to comment on the results of this analysis. The significance of cognitive decline is likely to be relative to other problems, particularly physical health, but the focus on cognition meant that the broader context might not be sufficiently prominent. Finally, it would be valuable to contextualise cognitive complaints in our group by comparing them with interview data from a population with normal performance on EF tests.

Conclusions

Person-centred care depends on a good understanding of individual needs, but there is limited research on how common executive impairments translate into the everyday functioning of people with PD. Our study provides insights into how EF impairments translate into everyday difficulties and explores potential factors that mediate their impact. Despite the sample having relatively mild executive impairments, a range of difficulties across several areas of everyday life was noted, with the significance of the difficulties dependant on personal circumstances. A thorough understanding of EF deficits, including how people with PD are likely to describe them, is critical for more accurate diagnosis and for developing truly person-centred and effective support programmes.

Declaration of interest

The authors report no conflicts of interest.

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Table 1. Demographic and medical characteristics of the participating people with PD (n=11). The order in which people with PD are listed reflects their performance in the Delis-Kaplan Executive Function System, with those who had less abnormal scores listed first.

	Age	Gender	Predicted full IQ	Years of education	SEC [^]	H&Y	PD duration (months)	LEDD	HADS -A	HADS -D	MMSE	ACE-R	FAB	Abnormal in D-KEFS ^{^^}
Mean	72.27	-	115.82	12.64	-	1.45	72.55	524.68	4.18	4.82	29.64	95.27	13.7	-
(SD)	(4.10)		(5.90)	(2.81)		(0.52)	(49.36)	(457.00)	(2.44)	(1.99)	(0.67)	(5.62)	(1.35)	
Range	65-77	-	103-124	10-18.5	-	1-2	12-156	140-1721.5	1-8	1-9	28-30	82-100	12-15	-
Alan	71	male	115	13.00	II	1.00	18	200.00	2	5	30	100	15	1
Barry*	65	male	120	15.00	III M	1.00	120	840.00	7	5	30	97	15	1
Collin*	71	male	103	10.00	III M	1.00	72	400.00	4	1	30	97	13	1
Dorothy**	77	female	118	11.00	III N	2.00	156	270.00	2	6	30	97	12	1
Eileen	69	female	112	15.50	III M	2.00	96	300.00	8	9	30	99	15	1
Florence*	73	female	113	10.00	III N	1.00	24	140.00	1	4	29	95	13	2
Hugh**	76	male	122	18.50	II	2.00	84	750.00	4	3	28	89	14	2
Gary*	67	male	115	14.00	II	2.00	36	550.00	4	5	30	100	15	3
Ian	77	male	112	10.00	II	2.00	132	1721.50	8	6	30	100	15	4
John*	76	male	124	11.00	II	1.00	12	400.00	3	5	30	92	12	5
Karen*	73	female	120	11.00	III N	1.00	48	200.00	3	4	29	82	12	5

D-KEFS – Delis-Kaplan Executive Function System; Predicted full IQ – premorbid intelligence level estimated by the National Adult Reading Test; SEC – Socio-Economic Class (possible range I-V); II – Managerial and technical occupations; III M – Skilled occupations manual; III N – Skilled occupations non manual; H&Y – Hoehn and Yahr stage; LEDD – total daily levodopa equivalent dose; HADS – Hospital Anxiety and Depression Scale (HADS A – Anxiety scale, HADS D – Depression scale); MMSE – Mini Mental State Examination; ACE-R – Addenbrook’s Cognitive Examination – Revised; FAB – Frontal Assessment Battery; *Spouse/partner interviewed, **Live on their own; [^]Based on occupation; ^{^^}Scaled scores ≤ 6

Table 2. Example quotes from all participants for each category. The order in which people with PD are listed reflects their performance in the Delis-Kaplan Executive Function System tests, with those who had less abnormal scores listed first.

		Cognitive problems				Behavioural problems	
		Global cognition & thinking	Memory	Attention	Processing speed	Apathy	Other behavioural problems
People with PD (n=11)		9 (82%)	8 (73%)	5 (45%)	4 (36%)	7 (64%)	4 (36%)
<i>Carers (n=6)</i>		4 (67%)	5 (83%)	2 (33%)	2 (33%)	5 (83%)	4 (67%)
Alan	1						[Talk at length about non-related topics.]
Barry	2	I've found I can't make a decision. I dwell on it for two, three or four days for something trivial.				I'd like to become a little bit more outgoing as possible just for my partner's sake.	
<i>Barry's partner</i>	2					<i>He won't really push himself to try either because I'm sure he could manage [going away for holiday]</i>	<i>I washed and ironed fifty shirts last week (...) but he still wants some nice shirts.</i>
Collin	3	Well [wife] in fairness [does planning], when we arrive [wife] will say 'right well we'll do, that that's it.	She [wife] remembers, reminds me to take me Warfarin.			I wash up a couple of times, not as many as I should do but you know I could do it more if I wanted to.	
<i>Collin's wife</i>	4	<i>Me yeah yeah oh yeah. [organise holiday]</i>	<i>I've caught him with a couple of times, he doesn't turn off the grill.</i>			<i>He doesn't concentrate, he doesn't finish anything.</i>	<i>Shouting through the window at him, more words that I couldn't repeat, you know, so yeah he does it other times as well.</i>
Dorothy	5	I have to think twice these days. Make sure I've got	Can't always think of the word right off.		It's the speed of things. I'm so slow		I've got indigestion again. (...) Feels

		everything right. [about finances]			I meet myself coming back.	like a lump of lead in the bottom. (...) Are you committed to anyone? (...) What happens if you have a baby?
Eileen	5	I think I'd find reversing a little difficult, and yet I used to be so good at it.	Yes, it's poor [memory].	I wasn't really concentrating because I felt it was such an effort to give, to be part of the conversation.	By the time I'd thought of what I wanted to say, the conversation would have gone on tenfold.	I can't be bothered to look. (...) a lack of energy but a lack of interest as well. [about shopping]
Florence	5	I think probably [husband] decides more where we're going and who with and when and whatnot. He...I'm just happy to go along and say yes.	Ah, yes, you forget odd things like that.	I find it difficult to concentrate on reading if there's somebody in the room asking questions or interrupting.	It's just automatic for me to do these things slowly.	I feel sluggish (...) I find it a big effort to do things.
<i>Florence's husband</i>	3		<i>You've got to write it down and then if you don't write it down you forget.</i>		<i>Gotta have a bit of patience 'cause she does things slow.</i>	<i>I think she's lost a bit of interest to tell you the truth, in the gardening.</i>
Hugh	3	I just don't know why, I don't know why I'm like this (...) and that annoys me because I was... I was fairly clever when I was younger.	I didn't retain enough of what he taught me to make it useful to me [computer class].	You can't absorb it like I used to absorb it erm your just sort of reading words.		
Gary	4	I couldn't get the machine to do what I wanted [cash machine]	I'll probably forget what she's told me a week later	I bring the same thing up in conversation and		Some days I really don't wanna go out the house really

Gary's wife	5	<i>To go from being so intelligent to not being very intelligent in my opinion that must be the hardest thing for him and it's the hardest thing for me too.</i>	<i>He was an extremely intelligent man and he can't remember simple things any more.</i>	<i>of course... not listening to it I mean he finds concentration and reading a book quite hard.</i>		<i>He always complains that he's got no energy and no get up and go.</i>	<i>He does a tape every night religiously.</i>
Ian	4	I know I should be doing it differently when I'm actually doing it.	I get into a programme that I've used for years, get part way through it and I suddenly don't know what to do next.		The tablets that she takes slow her down whereas the tablets I take speed me up and we have great difficulty in meeting in the middle.		Rather than stop and go and do it the right way I'll try and make what I'm doing work (...) but because I'm already in it I don't want to get out of it.
John	1						[Monologue with no space for questions]
John's wife	2	<i>I think he's not, he's feeling that he can't cope with it as well as he used to do</i>	<i>There are certain times when he cannot recall things.</i>				
Karen	5	It's like being in a plastic ball and I feel I'm not there, I'm not with it.	I can be told something and then after a few minutes I've forgotten it.	... What was the question?	It's made me slower mentally	I'm not going out so much and doing things, I try to because I think it's a good thing to do	
Karen's husband	6	<i>She's no longer fully in control of the pattern of her thoughts.</i>	<i>The fact she's been told verbally, and she had read it had not sunk in.</i>	<i>She has difficulty in holding on to a concept.</i>	<i>I could be around four isles while she's making her way up half an aisle.</i>	<i>If I was suddenly to die she could overcome quite reasonably (...) it's a perception that she can't do it rather than an inability.</i>	<i>She will stop what she's doing to scrape it off because she's seen it she's got to do it then.</i>